Using child- and family- centred goal setting as an outcome measure in residential rehabilitation for children and youth with acquired brain injuries: The challenge of predicting expected levels of achievement

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Introduction

There are a multitude of causes of acquired brain injury (ABI) in childhood including trauma, stroke, infection, tumours or hypoxia (Hayes, Shaw, Pearce, & Forsyth, 2017). Depending on the location and severity of the ABI, children can present with a range of physical, emotional, cognitive, communication and behavioural difficulties (Johnson, DeMatt, & Salorio, 2009). Children who sustain a severe brain injury often require a period of specialist child and family-centred, multidisciplinary rehabilitation to allow them to achieve the best possible outcomes, and to participate as fully as possible at home, school and in the community on discharge (Forsyth & Basu, 2015).

Collaborative goal setting between the clinical team and the child and parents is recognised as a key element of child and family-centred care (Brewer, Pollock, & Wright, 2014). Using this process to identify child and family priorities has been linked to enhanced engagement and motivation in rehabilitation, improved outcomes, and greater partnership between families and clinicians (King & Chiarello, 2014). Furthermore, the use of goals agreed with children and families to measure rehabilitation outcomes has been shown to be sensitive and meaningful, and able to detect changes not captured in standardised measures (Krasny-Pacini et al., 2013).

There is no literature investigating goal setting in childhood ABI, but research into goal setting in both adult stroke rehabilitation, and paediatric community therapy settings has highlighted challenges of achieving collaborative goal setting (Levack et al. 2011; Mudge et al. 2014; Brewer et al. 2014). One of the difficulties surrounds the setting of expected levels of achievements for the goals agreed with children and their families. Current evidence from the adult stroke literature suggests that ambitious goals are important for some individuals; but that for others goal achievement is the essential and motivating component (Brown et al.,

2014; Leach, Cornwell, Fleming, & Haines, 2010). Therefore setting an achievable, but challenging target level of goal achievement is likely to be important (Playford, Siegert, Levack, & Freeman, 2009).

It is known that children/young people with ABI form a highly heterogeneous population, for whom there is currently uncertainty regarding the prognosis for recovery of function, and participation (Forsyth & Kirkham, 2012). Therefore, predicting a child/young person's progress during their rehabilitation, in order to set the expected levels of achievements for goals they, or their parents, have prioritised is likely to be challenging. There have been studies considering the goal achievement levels of adults during brain injury rehabilitation (Turner-Stokes, Williams, & Johnson, 2009), and children with cerebral palsy (Steenbeck et al. 2009). However, there are currently no studies exploring this in children with ABI during residential rehabilitation. This study aims to determine the type of goals that are most commonly set by children and their families during residential rehabilitation, and how accurate therapists are at predicting the expected levels of goal achievement for these goals.

Method

This study was approved by [redacted] research committee on 5/07/2012. National ethical approval was not required due to the study being a review of routinely collected assessment data. All children and young people with an acquired brain injury admitted to a specialist residential rehabilitation unit in the UK between September 2013 and September 2016 (n=122) were included in the study. Goals prior to these dates were inconsistent in whether they were specific, measureable and timed, and were therefore excluded from the study.

The 24 bedded residential rehabilitation unit provides individually tailored multi-disciplinary rehabilitation programmes, typically lasting between 3 and 4 months, for children and young

people aged 0-18. Children/young people receive a daily rehabilitation programme consisting of physiotherapy, occupational therapy, speech and language therapy, psychology (where indicated), education and play, with 24 hour access to nursing and care staff who are trained in rehabilitation.

All participants had a severe ABI, defined as a traumatic or non-traumatic brain injury requiring the child or young person to spend at least 28 days in hospital (Hayes et al. 2017). All children/young people were assessed as having high rehabilitation needs warranting specialist residential multi-disciplinary rehabilitation (classified by the UKROC patient categorisation tool as having category A or category B needs (UKROC, 2013). Children were deemed medically stable prior to their admission. Within 3 weeks of admission, the child's named physiotherapist, occupational therapist or speech and language therapist completed a goal setting interview with the child and/or parents to establish their priorities for rehabilitation. Wherever possible the child's own goals were ascertained, with supportive tools such as Talking Mats® used to facilitate this process where required. If the child/young person had a communication device this was used in the goal setting discussions. Where the child was unable to communicate their own goals, due to age, or severe cognitive or communication difficulties, parents were asked to advocate on behalf of their child, and set goals that they believed would be their child's priority. If the child and parents had different goals then both sets of goals were included.

Goal setting interviews, structured around the International Classification of Functioning, Disability and Health (ICF) (WHO, 2017), were used to facilitate the child and/or parents to identify goals based on areas of priority for their child. Specific, measurable, expected levels of achievement for each of the child/family identified goals were set by the child's treating therapy team, with the expectation that they will be achieved during their rehabilitation placement. The most relevant professional or professionals lead on setting the expected level

of achievement for each goal (for example, if the child/parent had identified a physical based goal, their physiotherapist set the expected level, if it was based around speech their speech and language therapist set it, or if it was self-care based their OT set them). The whole treating clinical team discussed the expected levels of achievements with parents and young people, to ensure a team approach to goal achievement. Each child had between 3 and 5 goals at any one time. If the child was granted an extension to their placement, further goals were set. Expected levels of achievement were reviewed and scored on discharge according to the GAS Light scoring system, whereby the therapist decided whether the goals were achieved at the expected level, a little more or a little less than expected, a lot more or a lot less than expected, or there was no change (Turner-Stokes, 2009). All therapists conducting the interviews and setting the expected levels of achievement were employed as either experienced or highly experienced paediatric therapists, who had been working within a paediatric ABI rehabilitation setting for at least six months. All therapists had in-house training on goal setting and GAS light.

All goals were retrospectively linked to International Classification of Functioning, Disability and Health (ICF) (WHO, 2017) by two independent therapists, to a subsection level of detail (Stucki, 2005). Descriptive analysis of the chapter of goals set, and the level of achievement gained was conducted. Further analysis of the goals set within each subsection of the mobility chapter was undertaken as this was where the most goals were set. Table one shows some examples of goals set, therapists expected levels and how they were coded to the ICF.

<Insert table one>

Results

One hundred and twenty two children, setting a total of 860 goals were included in the study. Table two shows the demographics of the children/ young people included, and whether it was the child/young person, parent, or both who participated in the goal setting interviews.

<Insert table two>

<Insert table three>

The majority of goals set in this study (82%) were in the activities and participation domain of the ICF, with body structure and function and environmental domains containing 9% of the goals each (Table 3). At a chapter level, the three chapters that contained the greatest number of goals were mobility (29% of total goals), followed by self-care (19% of total goals) and communication (12% of goals) (Table 3).

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Overall, 70% of goals were achieved, with 46% achieved at the expected level, and 24% achieved a little or a lot more than expected (Figure 1). There were three ICF chapters in which more than 70% of goals were achieved at the expected level; neuromuscular and movement related function (within body structure and function domain), support and relationships and attitudes (both within the environmental domain) (Table 2). Within the activities and participation domain, where the majority of goals were set, goals achieved as expected ranged from 35% (general tasks and demands) to 59% (major life areas) (Table 3).

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When goals are further categorised to a subsection level it can be seen that the therapists in this study have been able to predict some items more accurately than others (table 4). Walking based goals and upper limb goals were predicted accurately only 38% and 39% of the time, as compared to changing body position that was predicted accurately 52% of the

time. Upper limb goals were more commonly underachieved, whereas walking goals were often overachieved.

Discussion

This study has demonstrated that during residential rehabilitation following severe ABI children and their families predominately select activity and participation goals involving mobility, self-care and communication. Prioritisation of these goals would be expected, as they contain activities that are tangible and meaningful to the child. Indeed, given that successful participation in activities at home, school and the community is the overall aim of rehabilitation programmes (Hamilton et al., 2017), consideration of these types of goals would have been encouraged.

There have been no other published studies specifically looking at goals setting in paediatric ABI residential rehabilitation. However, when comparing our results with studies conducted in other neurorehabilitation settings, it can be seen that the prioritisation of activities and participation goals parallels findings from studies with children with Cerebral Palsy (Löwing, Hamer, Bexelius, & Carlberg, 2011; Steenbeek, Gorter, Ketelaar, Galama, & Lindeman, 2011) (Turner-Stokes, Williams, & Johnson, 2009). Yet when comparing the chapters of activities and participation with the highest numbers of goals there is a difference between ABI residential rehabilitation, and community rehabilitation for children with neurological disorders. Although self-care was prioritised in all studies, community services set far more goals around productivity in school and leisure activities (Costa, Brauchle, & Kennedy-Behr, 2017; Vroland-Nordstrand, Eliasson, Jacobsson, Johansson, & Krumlinde-Sundholm, 2016) . This may be because children in those studies presented with different needs, or they had different priorities at that stage of their rehabilitation. Either way, it highlights that children at the subacute stage following ABI initially may have different needs to children with

developmental conditions, which reflects the unique skill sets sub-acute rehabilitation therapists require.

The results of this study have also shown that therapists set the expected levels of achievement for the goals identified by children/families at exactly the right level less than half of the time, indicating that accurately predicting the level of goal achievement is challenging. This may be due to the current lack of understanding and knowledge regarding potential recovery following a paediatric ABI (Forsyth & Kirkham, 2012). Furthermore, it might be the child's progress during rehabilitation that is difficult to predict as it is impacted upon by many factors, including those intrinsic to them (for example reduced motivation or reduced health status) or extrinsic to them (e.g. lack of opportunities to practice, lack of equipment or support to achieve the goal). This challenge is not unique to paediatric ABI residential rehabilitation. A study in an adult inpatient neurorehabilitation setting reported that just over half their goals were achieved at the expected level (Turner-Stokes et al. 2009) and a community paediatric service found less than half their goals were achieved at this level (Steenbeck et al. 2011). It would therefore appear that accurate prediction of goals 50% of the time should be regarded as the standard for clinical practice, and future research should investigate how this can be built upon.

In agreement with the other studies by Turner Stokes et al. (2009) and Steenbeck et al. (2011), this study found that the majority of expected levels of achievement for goals are set to a level which is either achieved, or exceeded. It could be argued that overachievement of a goal would be the best possible outcome for the child, and indeed, that would be true if goals were set at the correct level, whereby they were challenging yet achievable (Turner-Stokes, 2009). However, children may exceed some goals that were set at an easy level by therapists wishing to ensure success, stemming from a belief that setting goals that are not achieved will be harmful to patients (Mudge, Stretton, & Kayes, 2014). Several studies

conducted with adults with neurological injuries have indicated that patients found that undemanding goals were unhelpful, and more worryingly, took away hope, and damaged the relationship they had with their therapists (Baird, Tempest, & Warland, 2010; Brown et al., 2014; Levack, Dean, Siegert, & McPherson, 2011; Van Lit & Kayes, 2014). However, these studies were of adults with neurological injuries who set their own goals. This may therefore not translate to children with ABI, whose parents frequently set the goals for them, due to their age or severity of cognitive or communication impairment.

From the results of this study, it is difficult to ascertain whether there is a difference in accuracy of predicting the expected levels of achievement in different domains of goals. Environmental goals, such as implementing equipment or establishing support services, were achieved as expected most frequently. However, the numbers of goals in each category within the environmental domain were small, limiting the interpretation of this finding. Nonetheless, a greater ability to predict the outcomes of environmental goals is plausible as these are inherently more predictable with a knowledge of the services and support required. With regards to the goals falling within the activities and participation domains, there are some differences in the amount of goals that were achieved at the expected level across the chapters. However, chapters containing large number of goals, namely, mobility, self-care and communication chapters, had a much more consistent prediction accuracy rate. This may suggest that some of the fluctuations seen in the other activities and participation chapters are due to insufficient numbers of goals.

When goals were categorised further to a subsection level, some disparities in the accuracy of predication were seen. For example, goals in the mobility chapter, changing and maintaining body position were much more accurately predicted than either walking based goals, or upper limb based goals. Furthermore, in this study the therapists commonly set walking based goals at too low level, whereas upper limb goals are often set too highly. A possible

explanation for this is that due to the complexity of upper limb function, rehabilitation is frequently less successful than more gross motor functions, and therefore therapists aim too high with these goals. However, an alternative rationale for this disparity is that families and therapists prioritise walking based goals over upper limb goals at this stage of rehabilitation. This raises further questions regarding the variation between categories in goal-setting. Do therapists and families prioritise and target goals due to their perceived importance, leading to higher than expected achievements? Or, do therapists set unambitious goals in priority areas, to ensure attainment and thus protect families from not achieving high-priority goals? More research is required to determine why there is disparity in accuracy of goal prediction.

Limitations

There are limitations to this study, firstly in the methodology of the collection of the data. Goal setting interviews, and setting the expected levels for achievement have been carried out by numerous therapists, with differing amounts of experience in the use of GAS light. Although all therapists are at a specialist or highly specialist level, some will have been relatively new to the use of GAS as an outcome, which may have influenced the results of the study. Secondly, therapists of differing professions (physiotherapy, occupational therapy and speech and language therapy) conducted the goal setting interviews with the child and family, which may have influence the types of goals set. Thirdly GAS light was utilised as opposed to full GAS. GAS light is recognised as being easier to use clinically (Turner-Stokes, 2009), but this may limit the robustness of the results for this study.

Conclusions and future research

Prioritisation of mobility, self- care and communication goals by children and their families is evident in the sub-acute stage of rehabilitation and therefore rehabilitation services need to meet these needs. Further research is required to establish whether goals change throughout

this period of rehabilitation, and whether on discharge home goal priority areas more closely reflect those of children with developmental conditions in the community. This would be important information to assist in determining ongoing services for children with ABI in the community.

Furthermore, it is evident from this study that there are challenges with the accurate prediction of goal outcomes for a period of residential rehabilitation following ABI, which reflects other rehabilitation settings. Further research should consider whether more experienced therapists have a higher level of prediction accuracy, and/or whether regular training on goal setting could improve the accuracy of the prediction of expected levels of achievement. Therapists need to acknowledge this challenge when they are having goal setting discussions with the child and their family, so all parties are aware of the levels of uncertainty involved, yet do not feel afraid to set ambitious goals. This may facilitate more open conversations with families, allow therapists to set more challenging goals, and help families maintain hopes which they see as vital in the rehabilitation process. Future research should investigate child and family experiences of goal setting during paediatric ABI rehabilitation, to understand how the process can best meet their needs.

Key messages

- Clinicians working in paediatric acquired brain injury rehabilitation need to be skilled in offering interventions targeting mobility, self-care and communication, as these are the most common areas prioritised by children and their families.

- It is challenging for therapists to set the level of expected achievement for each goal accurately, which may be due to ease of prediction, factors related to the child and rehabilitation, or factors related to the therapists' confidence regarding setting goals.
- Therapists need to discuss the challenges of accurate prediction of goal outcomes with children/young people and their families, in order to facilitate honest and open conversations regarding goals, hopes and expectations.
- Research is needed to ascertain the families' experiences of goals setting in paediatric ABI rehabilitation, and how this process can best meet their needs.

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Figure 1: Levels of achievement of all goals

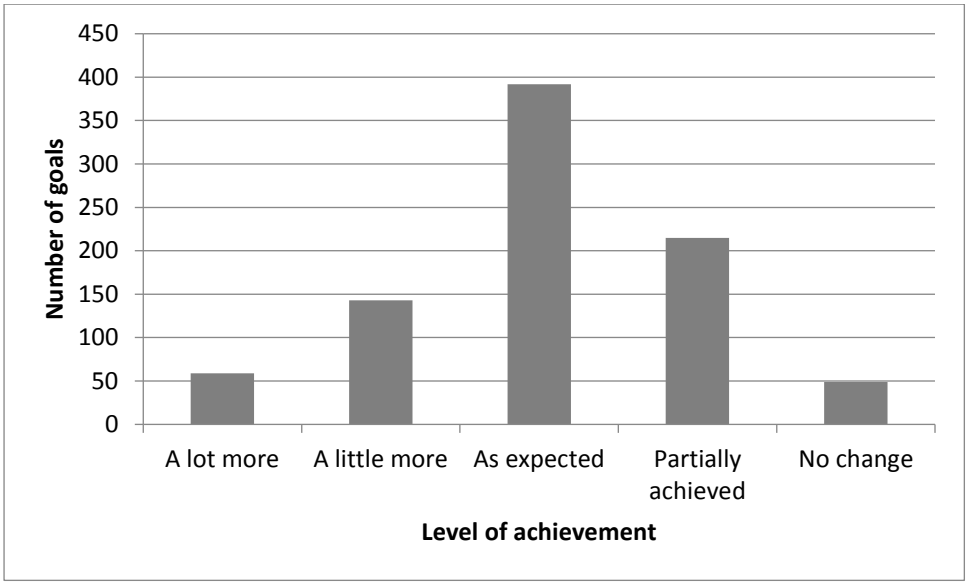

Table 1: Demographics of the children/young people and goals set in the study

Age at injury	Mean: 10 years, range 1-17 years, interquartile range 5-14 years
Nature of brain injury the children/young people sustained	40% trauma, 19% stroke, 15% inflammatory illness, 10% tumour, 9% anoxia and 7% other
Time between brain injury and goals set	Mean 5 months, interquartile range 3-7 months, range 1-31 months
Person participating in goal setting interview with therapist	65% parents, 12% child and parents together, 19% child, 4% no family representative

Table 2: An example of some goals set, expected levels of achievement and how they were coded.

Child/parent goal	Therapist expected level	Level of achievement	Who set the goal	ICF chapter child/parent goal	ICF chapter therapists goal

To be able to walk by myself.	For X to be independently mobile in his house with an appropriate aid.	As expected	child	d450	d450
To play his X Box One	X will be able to play his X box one with his friends.	As expected	child and parent	d920	d920
To speak to his family.	X will be intelligible at single word level in context with familiar communication partners such as his family/friends/familiar staff	A little more	parent	d330	d330
For X to go to school	A suitable school will have been identified for X.	Partially achieved	parent	d820	e585
For X to go to the toilet on her own	X will go to the toilet on house by herself throughout the day.	Partially achieved	child and parent	d530	d530
For x to be able to eat	X will manage a soft mashed diet.	A lot more	parent	d550	d550

Table 3: Goals and level achieved by ICF chapter

ICF Domain	ICF Chapter	Number of goals set by children/parents	Percentage of goals scored at the expected level	Percentage of goals over achieved	Percentage of goals underachieved
Body structure and function domain	Mental functions	33	60.6	18.2	21.2
	Sensory Functions	4	0.0	50.0	50.0
	Voice and speech functions	12	25.0	50.0	25.0
	Functions of cardiovascular and respiratory systems	3	33.3	0.0	66.7
	Functions of digestive and metabolic systems	11	9.1	18.2	72.7
	Genitourinary and reproductive functions	1	0.0	0.0	100.0
	Neuromuscular and movement related functions	17	70.6	11.8	17.6
Activities and participation domain	Learning and applying knowledge	68	36.8	30.9	32.4
	General Tasks and demands	20	35.0	10.0	55.0
	Communication	101	40.6	26.7	32.7
	Mobility	249	43.4	26.5	30.1
	Self-Care	165	46.3	24.1	29.6
	Domestic Life	8	50.0	16.7	33.3
	Interpersonal interactions and relationships	14	42.9	35.7	21.4
	Major life areas	34	58.8	20.6	20.6
	Community, social and civic life	48	52.1	16.7	31.3
Environmental domain	Products and technology	29	46.4	14.3	39.3
	Support and relationships	26	80.0	12.0	8.0
	Attitudes	2	100.0	0.0	0.0
	Services, systems and policies	17	40.0	0.0	60.0

Table 4: Mobility goals; Number of goals in each subsection, and level of achievement.

Mobility subsection	Number of goals	Percentage of goals achieved at the expected level	Percentage of goals underachieved	Percentage of goals overachieved
Changing and maintaining body position	93	51.6	32.3	16.1
Carrying, moving and handling objects	41	39.0	43.9	17.1
Walking and moving	100	38.0	23.0	39.0
Moving around using transportation	5	60.0	20.0	20.0